Chronic fatigue syndrome/myalgic encephalopathy

- Classified by WHO as a neurological disorder (ICD 10, 1969).
- Population prevalence of 0.2–0.4% (NICE 2006).
- Chronic fatigue syndrome/myalgic encephalopathy (CFS/ME) is often misunderstood.
- Pain is one of the most debilitating symptoms of this condition.
- 70% of CFS/ME patients have widespread pain and trigger points that are comparable to fibromyalgia.
- Aetiology unclear.

Diagnostic criteria

CFS/ME is a diagnosis of exclusion; Fukuda criteria (1994), recommends the following tests to exclude alternative pathologies: FBC, ESR/CRP, U&E, Ca, liver/thyroid, creatinine kinase, glucose, urinalysis, and consider autoantibody tests to rule out other differential diagnoses.

Referral criteria to specialist services may vary in relation to recommended clinical tests, but it is imperative that any other causes of fatigue are excluded.

Clinical features

Clinical features may include:

- Pain and fatigue causing significant functional impairment
- Muscle wasting due to loss of activity (often rapid)
- Deconditioning—as a result of increasing pain and fatigue
- Light and chemical sensitivity
- Frequent infections
- Impaired concentration span and cognitive impairment
- High levels of distress
- Withdrawal from exposure to others.

25% of sufferers will have significant disability.

Fatigue

Often confused with persistent tiredness but unalleviated by rest, presenting as lethargy and malaise:

- Triggered by physical exertion (mild to vigorous).
- Sleeping throughout or regularly during the day to compensate for unrefreshing sleep. This can lead to sleep reversal patterns, and disrupted bodily rhythm that is challenging to realign.

Pain

This is variable dependent on several factors including exercise, activity, physical condition, and general symptom presentation. Not all individuals with CFS/ME experience pain, but for others, pain is their primary cause of distress. Pain can take the form of:

- Joint pain without swelling
- Muscular pain comparable to fibromyalgic symptoms.

In the initial 'flare-up', muscular and joint pain may be experienced as well as fatigue; the convalescing period of illness and consequent inactivity leads to deconditioned muscles which can contribute to pain when resuming exercise (especially if resuming too quickly). The knock-on effect of this experience may be a routine devoid of 'pain inducing activities', i.e. exercise (see Fig. 11.2). This avoidance feeds into the cycle of deconditioning and consequent pain and, after a time, pervasive pain can be triggered by relatively short periods in any fixed position. It is also possible that pain is experienced independently of this cycle but it cannot be easily differentiated, formulated or understood: It can be pervasive and widespread and often goes untreated.

CFS/ME can also present with other clusters of overlapping symptoms such as hyperventilation and hypermobility, causing increases in both fatigue and joint pain.

Cognitive difficulties

Memory and concentration/attention span is a source of difficulty for individuals with CFS/ME. These areas seem to be:

- Subjectively impaired.
- Often without a clear and consistent pattern.
- Exacerbated by high levels of fatigue and inactivity.
- Often referred to as 'brain fog'; CFS/ME can cause:
  - Feelings of confusion.
  - Inability to concentrate.
  - Headaches, dissimilar to those prior to onset and triggered by exertion, light sensitivity and noise, can also present independently.

These symptoms are often considered the most debilitating, as impact on interaction and daily functioning can be severe. This can be extremely anxiety provoking and can lead to social anxiety, low mood, and difficulties around self-esteem and confidence.

Management and treatment

Treatment is primarily aimed at

- Increasing levels of daily functioning
- Improving subjective quality of life
- Improving sleep (medication may be prescribed)
- Reducing pain (medication may be prescribed)
- Tackling bacterial infections (medication may be prescribed)
- Improving mood or addressing anxiety.

Due to chemical sensitivity, some individuals may be unable to regularly take medication. Currently there is no drug treatment of choice that has an overarching effect on symptomatic presentation of CFS/ME.

Questions remain regarding aetiology and there is no universal understanding of the cause, so attention is turning toward a biopsychosocial approach, already adopted in the management other chronic conditions, including pain. The focus is on managing symptoms and experience, taking account of the social and psychological impact of the condition.

For example, an individual who suffers increased pain and fatigue whilst standing for prolonged periods wishes to be able to clean dishes as they previously did. Due to the difficulty in adapting to change, they may push on through the pain and fatigue to do so, precipitating a flare-up/exacerbation of their symptoms.

Many individuals who feel disabled by an 'invisible' illness such as CFS/ME feel forced to choose between managing the pain and discomfiture of performing everyday tasks they were quite capable of pre-onset, and the guilt and embarrassment they experience when having to ask for help or failing to complete the task.

Strong emotions such as loss, anger, and fear are often experienced due to the dramatic course that CFS/ME can sometimes take.

Fear of increased symptoms or the possibility of decline cause some to avoid physical or challenging activities due to the perceived potential for relapse or worsening of symptoms. Others push on through at the cost of high levels of pain and fatigue. This can be the beginning of a 'boom and bust' cycle that prevents physical reconditioning and symptom management.

The boom and bust cycle represents the pattern of activity which is found in pain-related conditions; individuals do more than usual on a good day and then suffer the 'pay-back' of a flare-up and increase of symptoms. Symptoms abate and the cycle may repeat on the next good day. This can link into other cycles such as activity avoidance or continuing activity through pain and fatigue.

These cycles can become well established and difficult to break, so early intervention is imperative.

Learning to exercise and pace is often experienced as unachievable and too challenging, whilst struggling with a change in health status and the transition to a life that is multidimensionally changed.

Aim of interventions

- Address the 'boom and bust' cycle
- Develop skills in activity pacing
- Encourage self-management.

As illustrated in Fig. 11.2, continued activity during a flare-up period can cause rebound and increased symptoms. On the other hand, avoidance of activity due to pain and fatigue and the consequential physical deconditioning can also cause a rebound effect.

Individuals with CFS/ME often suffer repeated flare-ups. Prior to the implementation of activity pacing and finding baselines to work from, it is important to highlight the potential rebound effects of both inactivity and activity, aiming to shift the flow into 'recuperative rest'. From this point, pacing, goal settings, rest, and baselines become fundamental in managing this condition when in a flare-up period.

Pacing

Pacing involves:

- Setting realistic targets and goals.
- Breaking down goals into manageable chunks.
- Breaking down difficulties into small goals.

Breaking down goals into manageable chunks gives a sense of achievement and encouragement, and also dispels the fear related to focusing on getting completely 'better' all at once. Breaking difficulties down into small goals involves challenging thinking patterns and belief systems, from ideas like 'I have to do this, I have to get better' to taking a more measured, realistic, and practical approach to symptom management and improving quality of life. This is the basis of goal-setting and working from baselines.[1]

This approach also aims to equip service-users with the necessary skills to manage their sleep patterns, pace exercise and troubleshoot everyday tasks.

Emphasis is placed on identifying coping strategies that no longer work and finding more adaptive strategies around managing a chronic health condition.

Importance should also be placed on tailoring routines of activity and rest to accommodate symptoms and also activities with high levels of personal enjoyment. These routines can be adjusted as individuals improve and move away from the 'boom and bust' pattern.

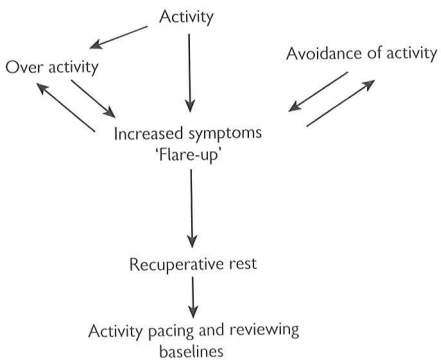

Fig. 11.2 The possible cycles of CFS/ME.

Rest

A significant aspect of this approach is scheduling appropriate recuperative rest. In the 'boom and bust' cycle, resting is often omitted but is an essential component to managing energy levels.

A good guide for the moderately affected is 10min every 1–2h. It is imperative that rest is used to recuperate and reduce the amount of pressure the body is under. 'Rest' represents a period without any stimulation which does not lead to sleep.

Activity schedules

Activity scheduling is a very effective behavioural intervention that highlights the amount of rest and physical or mental energy that activities demand: high, medium, or low. This should

- Indicate if a boom bust cycle exists.
- Identify if an individual is overdoing high and medium level activities.
- Enable an individual to plan energy management and rest in advance.
- Provide a strategy to prevent and manage relapse.
- Enable an individual to adopt a self-management approach to their condition.

Sleep hygiene

A primary intervention used in treating CFS/ME which encourages a move towards 'regular' sleeping hours and away from daytime napping. This is difficult to implement as symptoms often increase in severity during the period of change with positive effects not being immediate.

Scheduling more regular rests can assist throughout this transition although patients may struggle not to accidentally fall asleep, being used to sleeping in the daytime.

When successfully implemented there is often a definite shift in quality of life towards feeling able to lead a 'normal' life in relation to levels of social functioning and daily activities, and a subjective significant improvement in sleep quality and levels of pain and fatigue.

Reference

1 Gladwell P (2006). Practical guide for goal setting. In: Gifford L(ed). *Topical issues in pain 5*. CNS Press, Falmouth.